

## Racial/Ethnic Disparities in Hospice Care: A Systematic Review

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### ABSTRACT

**Context:** Access to hospice is a growing public health matter given that quality care at the end of life should be provided to all individuals regardless of race, ethnicity, or socioeconomic status. Health care disparities, particularly among racial and ethnic groups, have been well documented in the scientific literature. However, little is known about the demographics of hospice users or the use of hospice services by specific racial and ethnic groups.

**Objective:** This paper is a systematic literature review of studies that examine rates of hospice use among minority patients versus white patients.

**Method:** Comprehensive literature searches were conducted using the standard scientific search engines MEDLINE, PubMed, Psych Info, and the Cochrane Library for articles published from 1980 through January 2006.

**Results:** Twelve of 13 relevant studies found differences in hospice use between minorities and whites. The majority of studies were retrospective cohort studies using administrative data. No randomized controlled studies, meta-analyses, or any formal literature review were found.

**Conclusion:** Racial variations in hospice use indicate minorities use services disproportionately less than white patients, even after researchers control for specific sociodemographic and clinical characteristics.

### INTRODUCTION

HOSPICE AND PALLIATIVE CARE involve a team-oriented approach to provide expert medical care, pain management, and emotional and spiritual support. Despite the growth and acceptance of hospice in end-of-life care, it is estimated that of the 2.4 million people who died in the United States in 2000, only 1 of 4 was under hospice care at the time of death.<sup>1</sup> Emphasis on both quality of life and quality of care of individuals who are approaching death is an integral part of health care; yet for many Americans such expectations are not being met.<sup>2</sup>

Health care disparities, particularly among racial and ethnic groups, have been well documented in the

scientific literature. The Institute of Medicine report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* defines health care disparities as “racial and ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention.”<sup>3</sup> Clear disparities have been found in certain areas such as pain management, where there are significant gaps in the experiences and treatment of racial and ethnic minority persons.<sup>4</sup> Currently there is only fragmentary knowledge of the demographics of hospice users or the use of hospice services by specific racial and ethnic groups.

Providing quality, compassionate care for people facing life-limiting illness or injury is a priority for

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public attention and concern. To help ensure that hospice care is offered appropriately to all individuals who qualify, we must objectively review current trends in care to allow comparisons across different segments of society over time. This systematic review of the literature examines the evidence regarding differences in hospice use among minority patients versus white patients. If differences or disparities exist, an effort should be made to clarify research policy, and intervention efforts needed to eliminate such differences and disparities in order to improve the quality of care for all Americans.

## METHODS

### *Search strategy*

Comprehensive literature searches were conducted using the standard scientific search engines MEDLINE, PubMed, Psych Info, and the Cochrane Library for articles published from 1980 through 2006 addressing hospice use and quality end-of-life care for minorities in the United States. The following Medical Subject Headings (MeSH) terms and free text terms were included and combined (with "AND/OR") to maximize the results: hospice(s) (MeSH), hospice utilization, hospice use, hospice programs, racial and ethnic disparities, end-of-life care, advance directives, palliative care, pain management, race, ethnicity, differences, quality of life, terminal illness, do-not-resuscitate orders, acquired immune deficiency syndrome (AIDS), cancer management, living wills, decision making, mental health services, and critical care. To identify the studies that focused on race or ethnicity, the following modifiers were used: African Americans, blacks, Hispanic, Latinos, Hispanic Americans, Asian, Asian American, Pacific Islanders, Caucasian, white, as well as ethnic groups, racial groups, or minority.

Reference lists of published articles were reviewed and the electronic links to related were examined. Web sites and indices of the following key journals were hand-searched to identify other relevant articles possibly missed. Articles were included if they compared hospice use in minority versus non-Hispanic white individuals aged 15 years and older in the United States who received or were eligible to use hospice services (i.e., terminally ill), regardless of the cause of illness. Broad criteria for study design were used to include all possible types of studies, given that end-of-life studies vary depending on the use of administrative data, clinical data, or hypothesis-driven survey studies

and qualitative research. All available randomized trials were included to make the best possible use of available evidence. Articles were excluded if they were purely methodological in nature, case reports, case series, editorials or review articles, or if they were published in a non-English language, or published outside the United States. Studies that did not specifically analyze racial and ethnic groups with regard to aspects of end-of-life care and hospice utilization were also excluded.

## RESULTS

One hundred ninety-one potentially relevant citations were found. Of these, 129 abstracts were initially excluded using the established inclusion and exclusion criteria. Sixty-two studies were retrieved for a more detailed evaluation, of which 49 studies were further excluded after evaluation of the full text. A final group of 13 studies, published between 1998 and January 2006, met all the criteria set forth in this systematic review. Twelve studies found differences in the rate of hospice use between minority racial/ethnic groups and non-Hispanic whites. The majority of studies were retrospective cohort studies using administrative data to compare rates of utilization among minority groups and non-Hispanic whites. No randomized controlled studies, meta-analyses, or any formal literature review were found. There was wide variation in terms of data source, patient characteristics, and sample selection in terms of number and the combinations of racial and ethnic groups that had been used for analysis.

Among five studies based on SEER-Medicare Data, four reported differences in hospice utilization among racial and ethnic groups. Lackan and colleagues<sup>5</sup> conducted a study to examine hospice utilization as a function of patient characteristics, such as sociodemographic variables, geographic location, type of insurance, and year of death. The sample included 170,136 patients aged 67 and older diagnosed with breast, colorectal, lung, or prostate cancer from 1991 to 1996 and died between 1991 and 1999. Within each racial and ethnic group, hospice services were used by 31% of non-Hispanic whites, 27.3% of blacks, and 26.7% of other ethnicities ( $p < 0.0001$ ). Higher utilization ( $p < 0.0001$ ) was higher for non-Hispanic whites, those enrolled in managed care and those who were younger, married, female, living in urban areas, diagnosed with lung or colorectal cancer, and living in areas with higher education and income levels. The study showed that hospice use increased for both blacks and non-Hispanic whites over the study period,

but the higher ratio of use by non-Hispanic whites compared to blacks remained the same.<sup>5</sup>

Ngo-Metzger and colleagues<sup>6</sup> compared Asian and white Medicare beneficiaries who died of primary lung, colorectal, prostate, breast, gastric, or liver cancer between 1988 and 1998. The sample consisted of 184,081 patients of which 5% were Asian, of whom 45% were foreign born. Initial unadjusted analyses showed that U.S.-born Asians used hospice services similarly to U.S.-born whites. However, after adjusting for demographic characteristics, managed care insurance, year of diagnosis, tumor stage at diagnosis, and tumor registry, both U.S.-born and foreign-born Asians were less likely to use hospice than whites (Asian American [odds ratio {OR} = 0.67; 95% confidence interval {CI}: 0.62–0.73]; foreign-born [OR = 0.90; 95% CI: 0.86–0.94]). The authors reported that the same results were consistently found across six cancer diagnoses.<sup>6</sup>

McCarthy and colleagues<sup>7</sup> performed their study to examine the factors associated with hospice enrollment and length of stay in hospice among patients diagnosed with lung and colorectal cancer between 1973 and 1996 and died between 1988 and 1998. The authors found that blacks with lung cancer (25%) used hospice services slightly less than whites (27% and those of other race/ethnicity (26%). Blacks also had a significantly longer time to hospice enrollment compared to whites. With colorectal cancer, however, blacks were found to use hospice services more than the other two groups (black 23%; white 20%; other 20%) and no significant difference existed between groups in terms of time to enrollment. Interestingly, for both primary cancer sites, patients of non-white, non-black race/ethnicity had significantly longer times to hospice enrollment. The study further indicated white patients had a shorter length of stay in hospices compared to blacks.<sup>7</sup>

Using data gathered in a prospective cohort study, Gallo et al.<sup>8</sup> assessed the relationships between home death and a set of demographic, disease-related, and health-resource factors among individuals who died of cancer in Connecticut during 1994. Both bivariate and multivariate results showed that whites were more likely to die at home than non-whites (bivariate relative risk [RR] = 1.32, CI = 1.12–1.59; multivariate RR = 1.25, CI = 1.01–1.55). The study indicated that individuals residing in areas with more home hospice providers were more likely to die at home than in the hospital or an inpatient hospice (RR = 1.17, CI = 1.05–1.30).<sup>8</sup>

Of the five studies that used SEER-Medicare data, only one study found no differences in hospice use by

ethnicity. Lackan et al.<sup>9</sup> assessed the use of hospice by women dying with breast cancer between 1991 and 1996 as a function of patient characteristics, time period, and geographic area. They found significant differences ( $p < 0.001$ ) where patients who were younger, married, urban, with higher education or income, were more likely to use hospice care. However, they reported non significant differences in hospice use by race or ethnicity ( $p = 0.406$ ): white (20.7%); black (19.9%); Hispanic (22.5%); Asian (19.4%). Length of hospice stay did not vary by race/ethnicity, but rate of hospice use increased over time at similar rates for all categories of race and ethnicity.<sup>9</sup>

All four studies that used data from national surveys found differences in hospice use between racial and ethnic groups compared to whites. Greiner et al.<sup>10</sup> examined racial/ethnic hospice use variations in a national cohort using the 1993 National Mortality Followback Survey (NMFS). This sample of 23,000 individuals over the age of 15 who died of nontraumatic causes used death certificates and interviews with relatives (proxy respondents) to provide information about mortality, social and economic data, and information about health care utilization in the last year of life. Unadjusted bivariate results indicated African Americans were significantly less likely to use hospice than whites (OR 0.59,  $p < 0.0001$ ) and that those without a cancer diagnosis (OR = 0.28,  $p < 0.001$ ) and without a living will (OR = 0.23,  $p < 0.001$ ) were likely to use hospice.<sup>10</sup>

African Americans remained less likely to use hospice than whites even after controlling for gender, marital status, education, existence of a living will, medical history (stroke, cancer, diabetes, or chronic obstructive pulmonary disease [COPD]), religiosity, income, and access to health care ( $p < 0.001$ ). Having a living will did diminish the negative relationship between African Americans and hospice use. A sub-analysis of subjects aged 55 and older again showed African American race/ethnicity was negatively associated with hospice use. This study did not find statistically significant differences in the rate of hospice use between Hispanics or “other” and whites; the authors attributed this lack of detecting significant effects to the insufficient power of having small numbers of these individuals in the sample.<sup>10</sup>

Lorenz and colleagues<sup>11</sup> evaluated patient and agency characteristics associated with receiving unreimbursed hospice care by using discharge data from the 1998 National Home and Hospice Care Survey (NHHCS). Among individuals less than 65 years of age, hospice patients receiving unreimbursed home care were more likely to be of non-white and non-

African American ethnicity and race (OR = 5.712,  $p = 0.003$ ) and less likely to be older (OR = 0.937,  $p = 0.001$ ). Demographic characteristics, including race/ethnicity, were not found to be associated with the receipt of unreimbursed care among discharged patients greater than 65 years of age.<sup>11</sup>

Another study by Lorenz and colleagues<sup>12</sup> that used data from the 1997 California Office of Statewide Health Planning and Development (OSHPD) annual home care and hospice survey, evaluated the relationship of hospice profit status to patient selection and service delivery. A comparison of for-profit hospices and not-for-profit hospice with their respective demographic characteristics showed that there were indeed racial/ethnic differences in utilization of hospice services. Whites made up of 63% of for-profit hospices, compared to 73% of not-for-profit hospices. Non-whites, however, made up 37% of for-profit and only 27% of not-for-profit hospices ( $p < 0.01$ ). Bivariate and multivariate analyses further indicated that for-profit hospices served higher percentages of Medicare (77% versus 74%;  $p = 0.012$ ) and Medi-Cal (11% versus 75,  $p = 0.33$ ) compared to not-for-profit hospices; they also had more patients discharged prior to death than not-for-profit hospices (21% versus 14%,  $p < 0.001$ ).<sup>12</sup>

Cox<sup>13</sup> examined hospice care for persons with AIDS (PWA) by using a survey of hospices in the United States and Puerto Rico listed in the National Association of Homecare Hospices Directory. A comparison of patients in the 957 hospices surveyed revealed that PWAs were more likely to be black ( $p < 0.0001$ ) or Hispanic ( $p < 0.05$ ), younger, male, and covered by Medicaid. A comparison of PWAs in hospice with PWAs in the total U.S. population indicated that minority PWAs were underrepresented in hospice. Blacks make up 31% of all AIDS cases in the country, yet they made up only 24% of PWAs in hospice care; Hispanics made up 17% of all AIDS cases, yet only 10% of hospice PWAs; whites, however, were overrepresented, making up 52% of total national cases, yet consisted of 64% of PWAs in hospice care.<sup>13</sup>

Two of the 13 included studies which used Medicare hospice administration (claims) data from the Health Care Financing Administration (HCFA) also found racial and ethnic differences in hospice utilization. Virnig and colleagues<sup>14</sup> showed that across all types of cancers (bladder or kidney, breast, colorectal, esophageal or stomach, lung, pancreas, and prostate), blacks received approximately 82% of the hospice use as non-blacks. The black:non-black ratio for specific cancers are as follows (where a ratio of 1.0 indicates no difference in hospice use: bladder/kidney, 0.83;

breast, 0.89; colorectal, 0.83; esophageal/stomach, 0.82; lung, 0.83; pancreas, 0.83; and prostate, 0.75. These findings emphasize that differences in utilization exist regardless of differences in prognosis across cancers.<sup>14</sup>

Miller et al.<sup>15</sup> used HCFA claims data and standardized comprehensive assessments to study nursing home residents who enrolled in hospice care from 1992 to 1996 and died before 1998. Their data from five states (New York, Kansas, Minnesota, Michigan, and South Dakota) revealed that hospice patients were more often white than nonhospice patients. Multivariable analyses for entire hospice and non-hospice cohorts revealed that non-white individuals had a slightly higher probability of hospitalization (OR = 1.10, CI = 1.01, 1.19). The study did find that after adjusting for confounders, hospice care is associated with less hospitalization (OR = 0.43; 95% CI: 0.39–0.46). Compared to residents in facilities with no hospice, hospitalization was less likely for non-hospice residents in facilities with low hospice use (OR = 0.82; 95% CI: 0.80–0.84) and moderate hospice use (OR = 0.71; 95% CI: 0.69–0.74).<sup>15</sup>

Both studies involving community hospices found racial and ethnic differences in hospice care. A study by Colon and Lyke<sup>16</sup> from one community-based hospice in New Jersey indicated statistically significant differences in rate of hospice use among European American, African American, and Latino hospice patients [ $\chi^2$  (2,  $n = 1926$ ) = 246.62,  $p < 0.001$ ]. Hospice use for African-Americans was significantly lower than European Americans [ $\chi^2$  (1,  $n = 1894$ ) = 38.35,  $p < 0.001$ ]. African American use of hospice was found to decline significantly during this time period between 1992 to 1998, while hospice use by European Americans increased. Variables such as marital status, caregiver status, living situation, payment method, and referral source also contributed to differences found among the groups.

O'Mara and Arenella<sup>17</sup> examined the ethnic and racial makeup of a large metropolitan hospice facility in Arlington, Virginia, and compared its composition to the regional community in 1997. Results showed that Caucasians had the highest overall coverage of deaths by hospice care at 30%, while hospice services were used by only 20% of Asian decedents, 19% of Hispanic decedents, and 18% of African American decedents. Of note, cancer was the leading admitting diagnosis for racial and ethnic groups. The case study found a higher proportion of African Americans and Hispanics with an admitting diagnosis of HIV and AIDS. Caucasians had higher coverage for all causes of death, while coverage for other races was limited to primarily malignant neoplasms.<sup>17</sup>



## CONCLUSION

Even though efforts have been made to improve end-of-life care on an individual patient level, this systematic review demonstrates that improvements over the past decade are still not reaching certain segments of our population. Since there are no previous systematic reviews in the field of hospice utilization among racial and ethnic groups, the scope of this review is intended to be broad. The studies show statistically significant differences in rates of hospice use among African American patients compared to white patients; but overall were not adequately powered to show significant differences that might exist in Latino or Asian groups compared to whites.

There are limitations inherent to such a broad review. All of the included studies relied on administrative databases and may lack detailed clinical information on disease severity, clinical appropriateness of services studied, comorbid illness, functional impairments, and other information that may influence hospice use. The effect of reimbursement and financing factors also differed from study to study. The studies were conducted only on patients who had data regarding race or ethnicity available. Statistical power was inadequate to detect significant differences in some minority populations, such as Native American patients.

The majority of studies examined hospice use among older adults with cancer; it is unclear if the findings are generalizable to non-Medicare patients, younger patients, uninsured patients, and those with diagnoses other than cancer. The studies did not provide data on patient preferences, physician attitudes, timing of referrals, and refusal of health care services. Furthermore, the controls used in the studies were not consistent to allow for quantitative comparison; the presence of confounding factors may contribute to the difficulty of delineating the effects of race and ethnicity. Given that hospice usage patterns may change from year to year, the sampling frame in these studies may not allow for good comparisons between studies nor reflect current conditions of utilization.

Differences among racial and ethnic groups found here are similar to differences already reported in various types and levels of health care, ranging from diagnostic and therapeutic procedures, access to primary care, to organ transplants, to pain management. Even after controlling for specific sociodemographic and clinical characteristics, African American patients and certain other minority groups use services disproportionately less than white patients. Further initiatives beyond the scope of this review are needed to address

current barriers and find appropriate interventions to eliminate disparities in end-of-life care.

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